



## **Submission to the consultation on proposals for carers legislation**

We write on behalf of the Coalition of Carers in Scotland in response to the consultation on the government's proposals for carers legislation . We welcome the government's decision to bring forward legislation for carers and introduce new rights and entitlement to support. This is something which our members have been campaigning for over many years and the reason why we introduced the strapline 'From Recognition to Rights' in 2012.

### **1. Information on the Coalition of Carers in Scotland**

1.1 The Coalition was established in 1998 and represents over 90 local carer organisations . We are the largest network of local carer organisations in Scotland..

1.2 The Coalition's priority is to promote carer engagement and represent the carers' voice in national policy discussions. We have a proven track record in engaging carers in consultation to inform the development of social and health care policy

### **2. How we consulted and gathered evidence**

2.2 During the consultation period we endeavoured to consult with as many carers and other key stakeholders as possible and to raise awareness of the proposals and the opportunity for carers to have their views heard. Through consultation events, an online survey and social networking we were able to reach carers in almost every

local authority area in Scotland. An appendix providing further details on our methodology is included in this submission.

### **3. Introduction and Overview**

3.1 Our submission brings together the views of carers and local carer organisations from across Scotland. In consulting with our members we sought to reach a balanced view of each of the proposals, looking at what outcomes they had the potential to deliver for carers, identifying any negative impacts that could arise from their implementation and suggesting ways in which they could be strengthened or added to in order to maximise the benefits for carers.

3.2 Overall the people who engaged in the consultation were enthusiastic about the proposed legislation. Carers in particular were adamant that their priority for the legislation was to deliver tangible rights to recognise and support them in their caring role. Many carers strongly expressed the view that rights were ‘overdue’ ‘deserved’ and an important recognition of the money they save society by providing care on an unpaid basis.

*Carers Rights should not be seen as a political issue, but a human issue, a community concern, a common responsibility which does and will effect all of us at sometime in our lives. Caring for Carers and securing their rights should never be allowed to be seen as an issue dealt with at ‘the discretion’ of those in power. Rights are never a privilege, they are the fundamentals which underpin a caring and law-abiding society. (carer, Argyll and Bute)*

*We are saving the government millions each year (carer, West Lothian)*

3.3 There was some cynicism from carers and local carer organisations about whether the legislation will make a real difference to carers lives. There was also frustration about the length of time it will take to become law and translate into practice. However, even where these views were expressed the conclusion was still

that legislation was the right course of action and had the potential to improve carers lives

*Always, always a duty. If left to guidance it will never happen. (NCO survey)*

3.4 This was also borne out by the responses to our message boards when we asked the question 'Do you think that these proposals, if they are implemented, will make a significant difference to carers' lives?' At all of the events where we asked this question 100% of participants answered 'Yes' (COCIS member meeting, Stirling, South West Glasgow, Alloa, North Lanarkshire and the Borders)

## **4. Carer's Assessment / Carer's Support Plan**

*'He can do anything from his big chair' (carer, West Lothian)*

4.1 We know from previous research that carers' experience of the assessment process varies considerably across the different local authorities and uptake is still poor. Only 38% of carers surveyed for the Carers Rights Charter had been offered an assessment and of those who had an assessment, only 31% received additional support as a result.

4.2 In some areas carers spoke about having had a good experience of accessing a carers assessment. This was often in areas where carers assessments are carried out by local carer centres (Stirling, Borders, East Dunbartonshire)

4.3 In many areas carers had a negative experience of asking for or receiving a carers assessment and were keen to see improvements.

### Changing the Name and removing wording about carers ability to provide care

4.4 86% of people who responded to the NCO survey, agreed with the name changing from carers assessment to Carers Support Plan and support was unanimous at local consultation events

As one participant commented 'language heralds intent' The term assessment led many people to believe their competence as a carer was being assessed. With one carer calling carers assessments 'Embarrassing and degrading to families' (carer, COCIS meeting)

4.5 In some cases this perspective may also have been shared by staff undertaking carers assessments.

*Previous Carers 'Assessments' in West Lothian felt more like an examination of the Carers Competence and ability to Care. I never felt it was supportive (NCO Survey)*

4.6 Carers feel that changing the name to Carers Support Plan will place emphasis more firmly on supporting carers and planning for their current and future needs.

*The term Carers Support Plan expresses the intent much more clearly, but carers still want the choice of who carries out the assessment (carers, North Lanarkshire)*

#### Removing the substantial and regular test

4.7 This was widely supported by both carers and staff who felt it would enable carers to access information and support at an earlier stage. Many local authorities do not currently apply the substantial and regular test and this was felt to be working well.

4.8 99% of respondents to the NCO survey agreed that the substantial and regular test should be removed and only one respondent at our consultation events disagreed.

*An assessment should be a conversation (initial) It can 'weed out' complex support – **key to have it early** (COCIS meeting)*

#### Changing the requirement for the cared-for person being in receipt of services

4.9 This was felt to be an important distinction in separating the carer's needs from the needs of the person they care for.

Examples were given of carers with multiple caring roles, which individually were not enough to warrant support, but in combination made for an intensive caring role. There are also situations where the condition of the cared-for person fluctuates or where they have particularly complex needs, making it difficult for them to access suitable or ongoing support.

4.10 There are also many situations where the cared-for person does not acknowledge how much help they require and refuses to take-up any kind of support, relying entirely on their unpaid carer. This situation was illustrated by a carer in North Lanarkshire who was in her eighties. She described how her husband on being assessed told staff that he 'didn't require help as he was perfectly able to manage himself' failing to acknowledge that his wife did everything for him. This meant that she had been unable to access much needed support to protect her own health and wellbeing. Her comment on this was:

'He can do anything from his big chair'

#### Timescales for undertaking a Carers Support Plan

4.11 Carers welcomed an improved approach to legislate for local authorities to have a process for informing carers of the time it will take until they receive a Carers Support Plan. Currently carers can wait many months (indeed years) for their Carers Assessment. However, carers expressed a preference to have a maximum waiting time of a reasonable timescale (i.e. not exceeding 12 weeks) to ensure that carers do not reach crisis point before they receive support

*The timescales for receiving support from the local authority once an assessment as been completed must be improved (Third Sector Older Persons Services Forum, Stirling)*

*Speed of access to Carer Support Plans and services. Timeframes and targets should be set for the assessment and receiving of services (carer, West Lothian)*

*Maximum waiting time for assessments – 6 weeks is reasonable (carer, Borders)*

#### How should Carers Support Plan be carried out?

4.12 Most of the discussion around Carers Support Plans were focused on the importance of getting the process right, having an outcomes approach and ensuring it leads to carers being able to access the resources they require.

*Doesn't matter what it is called as long as I get a service (carer, South West Glasgow)*

*It needs to provide a sense of outcome that is monitored (COCIS meeting)*

4.13 In terms of who should carry out the assessment, of those who expressed a view, most were in favour of a local carer organisation undertaking assessments

*Carers centres are best placed to carry out carer support plans as what they do is all based around carers needs (COCIS meeting)*

4.14 This is supported by evidence from a survey of 714 carers in Lothian in 2013. Carers were asked what agency they would prefer to be responsible for carrying out carers assessments. The majority of respondents (58%) said they would prefer to be 'assessed' by a local carers centre or carer organisation. 25% said the NHS or someone from an organisation supporting the person receiving care. Only 9% named local authorities as their preference.

4.15 The view that carer organisations are best placed to carry out Carers Support Plans, was also supported by staff from the statutory sector. They expressed concern that they would not have the resources to carry out assessments if there

was a significant increase in demand. They saw devolving responsibility to the third sector as a practical way of fulfilling their responsibility.

*I agree that carers have to be recognised fully but as A CPN we are already expected to care manage and this is another piece of work (support plan) we will probably be expected to complete. We are already stretched and are struggling to even carry out our work as CPNs due to other social issues we are expected to do. Our core work as Psychiatric Nurses is being eroded over time and patients will suffer. Carers support plans really should be completed by staff at the Carers Centres to allow professionals like ourselves to concentrate in other aspects of care. (NCO Survey)*

4.16 However, for many it was more about the outcomes of the assessment, rather than who undertakes it.

*It doesn't matter who carries out the assessment – statutory or voluntary sector. It's the quality of the assessment that matters – there should be clear outcomes (carer, North Lanarkshire)*

*The Carers Assessment is only of value if the needs identified are met i.e. access to supports and resources follows on. There should be guidelines about the timescales for undertaking and implementing a carers assessment (carer, Borders)*

4.17 One thing was clear. A good assessment process involved meeting with someone on a one-to one basis and being supported through the process

*We were just sent the form and told to fill it in - what if people struggle with reading and writing? (carer, Alloa)*

## Review Process

4.18 The process for reviewing a Carers Support Plan was thought to be essential as caring circumstances and the caring role can fluctuate and in many cases conditions are progressive and changes are entirely predictable. COCIS's Rural and Remote Carers Group suggested

*Carer Support Plans should be reviewed as a minimum, once a year, unless there is an agreement by the carer that there is unlikely to be change during this period. In addition the carer must be able to trigger a review if there situation changes, whether this is one week after the initial support plan is agreed, or one year. (R and R group)*

4.19 For many carers reviews were not built in to the assessment process, making them quickly redundant

*I had an assessment around 10 years ago... Things have changed dramatically but not been offered another one – (Carers Rights Charter survey)*

#### Emergency and anticipatory Planning

4.20 A good Carers Support Plan should address emergency and anticipatory planning to allow carers to plan for the future and have comfort in the knowledge that plans are in place should they be unable to care at any point.

4.21 ENABLE Scotland has produced the research report 'Picking Up the Pieces' This sets forward a set of recommendations for establishing the provision of support to carers with emergency planning across all local authority areas. The recommendations include an emphasis on early intervention and prevention to avoid crisis situations and embedding consideration of emergency planning within the carer's assessment process.

*We had a recent experience which showed us that, while we all hold a good deal of information about my sister's routines and needs, there is a great deal only in*



*my Mum's head. It probably would be a good idea to work with her to get it all written down. (ENABLE Scotland, Picking up the Pieces)*

## **Strengthening the proposals around Carers Support Plans**

We are suggesting the following additions to the legislation / regulations and guidance, to ensure that the proposals in relation to Carers Support Plans produce the positive outcomes intended.

- **Third Sector Involvement** - We support the option to devolve the process for undertaking Carers Support Plans to the third sector. However, our position is that there needs to be an understanding that the duty still sits with the local authority and there must be a clear process for picking up on needs identified through the assessment. In terms of best practice this should include identified workers from the local authority linking with the third sector organisation.
- **Resourcing the Third Sector** – Where responsibility is devolved to third sector organisations, they need to be adequately resourced to undertake Carers Support Plans with additional staff funded to increase their capacity.
- **Timescales** – We believe that there should be a maximum waiting time for accessing a Carers Support Plan, of not more than 12 weeks. In addition there should also be a maximum waiting time for services to be put in place following a Carers Support Plan where a carer meets the eligibility criteria.
- **Review Process and Emergency and Anticipatory Planning** – We propose that the duty to provide a Carers Support Plan should include the duty to review Carers Support Plans as previously described and to incorporate emergency and anticipatory care planning into the process.

## 5. Information and Advice

*Whether you are a new carer or have been a carer for some time the walls you hit are ridiculous when trying to get information support and help (carer, West Lothian)*

Introducing a Duty for local authorities to establish and maintain a service for providing carers with information and advice

5.1 Support for this proposal was unanimous, with 100% of respondents to the NCO survey and those who indicated their views via message boards at our consultation events saying YES to the introduction of the duty.

### **Quality of Information Provision**

5.2 The provision of good information and advice was seen as a key priority by carers and many carers indicated they had struggled for many years to find information on services and support and the condition of the person they care. When a reliable source of information is found it is greatly valued.

*Good information and advice makes carers more independent and less dependent on LA services (COCIS meeting)*

5.3 The quality of information and advice offered to carers was identified as being key to the success of this proposal. Information and advice needs to be more than a leaflet, or website. It needs to be local, providing a range of information leading to access to support where required and it needs to be fully resourced.

*Important this is not on-line only based information. People need information to be made live and relevant to them and their situation, Moreover, need to be sanctions if this duty is not met otherwise meaningless (NCO survey)*

*We need more than a leaflet. They should signpost to relevant organisations where they already exist and link better with third sector organisations (carer, West Lothian)*

*worries about how the duty will be interpreted by councils but with this one I think there is a huge role for the 3rd sector to be involved (NCO survey)*

*There should be nationally agreed standards if information and advice provision, but differing ways of administering and delivering this based on local needs (Third Sector Older Persons Services Forum, Stirling)*

*In addition, if there is a duty then there must also be secure funding to services to ensure that carers in all local authorities receive the same high level of service. (Carers Voice Stirling)*

5.4 For many carers this service was accessed through their local carer centre and they indicated that this was their preference in relation to the future provision of information and advice in their area.

*The carers centres are well set up to do this work and their expertise should be recognised and paid for (NCO survey)*

*Everyone agrees that North Lanarkshire Carers Together (and carers centres generally) should be commissioned to provide information and advice (carer, North Lanarkshire)*

5.5 This is backed by evidence from the Carers Rights Charter Carer Survey in which carers were asked where they found out information about their rights. The majority 78% found out from a local carers organisation or a condition specific group.

*Yes, and it should be provided by a local independent carers centre who can provide independent advocacy and advice, not by social workers (NCO survey)*

## **Carers in remote and island communities**

5.6 COCIS's Rural and Remote Carers Working Group identified particular challenges to providing information and support to carers living in rural and island communities. For example, there is currently no dedicated carer support service on the Western Isles and carers are signposted to the community care forum. Many carers phone a carer volunteer from a local support group who tries to signpost them to help where it is available. Local information in very remote areas therefore needs to be very local and not just based in the nearest town which may be inaccessible to carers.

*There is a need for local information on a micro level. For example on Western Isles, what is available for someone in Stornoway will not be the same as what is available on Barra. There is a need for locally available information (carer, COCIS Rural and Remote Group)*

5.7 Examples of good practice were identified as outreach workers (Argyll and Bute, Shetland and Stirlingshire) and a virtual carers centres linked to a central carers centre acting as a hub (Shetland)

5.8 The duty on local authorities to provide information and advice is a welcome one in areas which currently have no provision, but they will need to look at more creative solutions on island communities.

## **Potential Unintended Consequences**

5.9 The one concern which carers raised in relation to the duty was that that Local Authorities may try to establish their own services, rather than resourcing existing carer support services. Or that they might put the contract out to tender and pick the cheapest provider.

*We need to watch for unintended consequences in the legislation – e.g. a duty to provide information by Local Authorities to carers could result in funding restrictions to carers centres and diverted to services in the private sector who could do job cheaper (but not better). We could end up with a dilution and weakening of services to carers. (COCIS meeting)*

*There are worries and concerns that local authorities would place funding restrictions in response to a duty being imposed and put the services out to tender (carer, North Lanarkshire)*

*Expertise is needed to support carers – not some fly by night group coming in (carer, West Lothian)*

*Concerns if it goes out to tender – things that are working well should be replicated (carer, West Lothian)*

#### Repealing section 12 of the Community Care and Health (Scotland) Act 2002

5.10 75% of people who responded to the NCO survey were against repealing section 12 and removing the obligation on Health Boards to produce a Carer Information Strategy. There were fears that this would result in health no longer prioritising carer identification and support

*Health boards are still slow to understand the needs and role of carers and involve them fully. The duty to provide information keeps them focused on the existence of carers (NCO survey)*

5.11 There was also the fear that some of the best practice developments which have been resourced through CIS funding would be lost and that health would not continue with their financial commitment to support projects if Section 12 is repealed. In particular, there were fears that carers support posts would no longer be funded and valued and experienced members of staff would be made redundant.

*Who is to say that the money will be ring fenced and used for carers support???*  
*(NCO survey)*

*If there is no longer a requirement for the NHS to produce Carer Information Strategies what happens to the money? The money needs to continue (carer, North Lanarkshire)*

*Some North Lanarkshire Carers Together staff members are funded through the NHS Carer Information Strategy. When funding runs out, or there is no longer a requirement to produce a NHS Carer Information Strategy, what will happen to these staff and who will pick up the excellent work they do for carers? (carer, North Lanarkshire)*

## **Strengthening the proposals around Information and Advice**

- **Quality Support Framework** - Our position is that there needs to be a quality support framework for carer information services and carers must play a central role in deciding who provides the information service in their area, taking account of existing services. Furthermore it is essential that carer information and advice services are based **locally**, are **independent** and also take account of the needs of more isolated carers, such as those living in remote and island communities and within BME communities

*Bringing in this duty could also mean protecting the key existing services, however it is crucial that carers have their say locally on what is working well and who the best provider of information and advice is. Carers must be treated as equal partners and involved in shaping the support services that meet their individual needs. (Carers Voice Stirling)*

- **Continuation of CIS** - In relation to the proposal to repeal the requirement for Health Boards to produce a Carer Information Strategy. Our view is that if this duty is repealed there needs to be a continued focus from health in identifying, informing and supporting carers, including directing resources to carer support as a continuation of CIS funding. The mechanisms for directing resources to

carer support need to be nationally agreed and embedded within the new integrated partnerships

*Do we need carer info strategies? – no but we need funding that has been invested in carers information and support services that came with it (COCIS meeting)*

## **6. Support to Carers (other than information and advice)**

**We don't really want that much – some acknowledgment and a little support" (carer, Alloa)**

6.1 The majority of carers who either attended a consultation event or responded to our online survey indicated that they agreed with the proposal to introduce a Duty to support carers and young carers linked to an eligibility framework.

6.2 94% of carers who responded to our survey gave a positive response to this proposal and at many of our consultation events the approval rate was 100% (Stirling, South West Glasgow, Alloa, North Lanarkshire and Borders) The lowest response came from those who attended the Coalition of Carers meeting in Glasgow where 63% of participants indicated that they were in support of this proposal.

*Carers are frustrated that they have a right to a carer's assessment but no right to the support and resources they are assessed as needing (COCIS meeting)*

6.3 Carers were clear that they wanted a right to support and greater transparency in regards to what level of support they are eligible for. They understood that by introducing an eligibility framework this could result in some people losing out, either because they do not meet eligibility criteria, or because the level of service they currently receive could be reduced. However, they felt that this was a fairer way of allocating resources and would help to address the postcode lottery and bring some clarification to the question 'What am I entitled to?'

*I have real reservations about how this will be interpreted but the need for a **duty** to provide services either directly or indirectly is clear. (NCO survey)*

6.4 In terms of carers who would not meet eligibility criteria there was universal support for the proposal to retain the discretionary power to support carers in these circumstances. This would include forms of preventative support, such as support from a local carer organisations or condition specific organisation, short break voucher or grant schemes or signposting to local community support

*There should be a duty to support carers against an eligibility framework, but local authorities should still have a power to support carers who don't meet all the necessary criteria (carer, North Lanarkshire)*

## **Why carers support the proposal**

### Knowing your entitlement

6.5 This was the most commonly voiced reason for carers supporting the duty. Many carers talked about the difficulties they had experienced with working their way through the system and accessing appropriate support. Phrases such as 'battling' 'fighting' 'hitting the wall' were used to describe how frustrating the process was.

*It should be a duty to provide a break for carers, and carers should not feel like they are begging (COCIS meeting)*

6.6 Carers felt that if local authorities have a duty to provide them with support and publish their eligibility criteria they would find it easier to navigate the system and access support

### Greater consistency



6.7 At the moment there is little consistency in what support is available to carers from one local authority to another. Indeed there are often inconsistencies in the support carers can access within local authority areas, either because it is dependent on the care manager, the tenacity of the carer in accessing support, or the suitability of available services for the cared-for person. Carers UK State of Caring Survey (2013) found that nearly a third of those caring for over 35 hours a week receive no practical support with caring. At our consultation events there was a great variation in the level of support carers were able to access, with some carers still struggling to access support despite having an intensive caring role

*Protects **all** carers not just carers who are lucky enough to live in a well-resourced area (COCIS meeting)*

*We need common sense legislation that ensures equality and maintains standards of support (carer, North Lanarkshire)*

*There needs to be equality across the board – everyone assessed using the same eligibility criteria with the same entitlements to support and resources (carer, North Lanarkshire)*

### Recognition

6.8 Carers felt that the government's decision to bring forward legislation for carers was an important step in recognising carers and their contribution to society. It also recognises the need to support carers and places a statutory responsibility on local authorities to support them for the first time.

*I feel it is important that a Duty is placed on the local authorities to recognise the role I play and should provide me with appropriate supports which meet my needs (South Asian Focus Group)*

*About time - heavy end carers should be prioritised as a matter of urgency (NCO survey)*

*There is a need for Carers Legislation to ensure carers are seen as a priority in Scotland (carer, South West Glasgow)*

#### Investment in services / Better use of resources

6.9 If local authorities are required to provide support to carers who meet eligibility criteria there will be a greater onus on them to ensure they have sufficient and appropriate provision in place to meet demand. Many carers we spoke to believed that money could be spent more wisely within the current system and those savings could be re-invested. However they also believed additional resources would be required and that local authorities should invest in carer support with a view to sustaining the caring population. This investment must be weighed against the known benefits of preventative support and the savings made by crisis prevention and avoiding the need for more costly interventions. Overall they felt that the Duty would require local authorities to prioritise carer support and start to 'fill in the gaps' that currently exist in provision.

*Impact will be that more resources will be required or existing resource will be diluted (a see-saw effect) However, if done in partnership between local authority and health with pooled budgets it will achieve better outcomes for people (carer, West Lothian)*

*There are different degrees of caring so there needs to be eligibility criteria to ensure a fair allocation of resources (carer North Lanarkshire)*

*The 'marketplace' needs to have more within it and this happen through support of the voluntary sector to develop options etc. (NCO survey)*

#### Supporting carers health and wellbeing

6.10 *The State of Caring* survey also found that 84% of carers surveyed said that caring has a negative impact on their health. Accessing quality, timely support can help to maintain a carers health and wellbeing, yet the study Rest Assured found that the barriers preventing carers from asking for help included: a lack of appropriate provision, guilt and uncertainty about eligibility criteria.

6.11 Carers often become frustrated with trying to navigate their way through the system and drop out, only to re-emerge later when their needs become greater and they are in crisis. A Duty to support carers would address some of these barriers meaning carers could access support at an earlier stage and potentially avoid crisis.

*Carers provide a vital service and, like the paid work force, should have rights and entitlements to enable them to continue to care this without risk to themselves (COCIS)*

*There are more demands placed on carers with more people being supported at home (carer, South West Glasgow)*

#### Enabling carers to challenge decisions

6.12 One of the frustrations carers experience at the moment is that when they are told there is no support available to them, there is no way for them to legally challenge this, as there is no statutory responsibility to support them. Many carers expressed the view that they would like 'to know where I stand' and be able to challenge decisions. A duty would begin to set out what carers can and can't expect in relation to available support

*They need to be held accountable (NCO survey)*

### **Potential Unintended Consequences**

6.13 While the majority of carers support the proposed duty and believed it would produce positive outcomes for them, there were still concerns that it has the potential to result in some negative impacts for carers. Most concerns centred

around the development of the eligibility framework, the successful implementation of the duty and what resources would be available to support it.

Eligibility criteria may prevent carers getting a service

6.14 Carers were concerned that the eligibility to receive support may be set too high, meaning only carers in crisis would be able to access support.

*Who supports those who don't meet eligibility? (COCIS meeting)*

*It is important that the eligibility framework is not placed at too high a level meaning many carers would be ineligible for support (NCO survey)*

*It is good to know what you are entitled to - but as I said before, if the eligibility is set too high, people at risk of reaching breaking point in their own situation could be let down. Perception of the personal circumstances and the effect on day to day life is what matters. (NCO survey)*

*COULD MEAN PEOPLE LOSE OUT (NCO Survey)*

Locally developed eligibility criteria may result in huge variation

6.15 Carers were very keen that the legislation would reduce the inequality faced by carers across Scotland and lead to greater consistency in accessing support.

However, they felt that if each local authority was responsible for developing their own eligibility criteria, this would not reduce inequality and there would still be the potential for massive inconsistencies within the system, with carers from one local authority able to access a much higher level of service than those in another. They were comfortable with the idea that each area may develop different types of support, according to local need, but were not persuaded that there should be variation in the eligibility criteria. This view was unanimous across all of our consultation events.

*A centralised (national) criteria is absolutely essential because it is currently disjointed resulting in unfair approaches in some areas. There should be a*

*minimum offer of support so that nobody receives less than the minimum (carer, West Lothian)*

*Eligibility criteria must be national – don't want people moving area to get a better service (carer, Borders)*

Eligibility criteria may not take into account the complexities of people's caring roles and their life outside of caring

6.16 There was an understanding that developing eligibility criteria is a complex area, particularly for carers, who are a diverse group and whose caring roles are also extremely varied. There are many factors that would need to be considered.

6.17 One thing is clear, it would not be a simple case of using existing eligibility frameworks, such as those used for other care groups.

6.18 The Western Isles are considering introducing an eligibility framework for carers access to short breaks based on the same model for disabled people which categorises people into different risk categories based on the intensity of their caring role (Critical, Substantial, Moderate and Low) We believe this model is too narrowly defined. Any eligibility criteria needs to take into account the complex nature of caring, including:

- The intensity of the caring role
- The impact of the caring role on the carer
- Other factors outwith the caring role which impact on the carers life, such as other dependents, employment status etc
- The carers health and wellbeing
- Additional risk factors such as the age of the carer and any progressive nature if the cared-for person's condition

6.19 In addition it needs to take into account the carers willingness to care and their ability to have a life outside caring.

6.20 Carers were clear that they should play a central role in the development of an eligibility framework as they are the experts in knowing what factors can impact on a person's life and contribute to them requiring support in their caring role. It is not as simple as looking at the number of hours caring / intensity of the caring role.

*This needs to be very carefully considered - with input from people who know what it is like to be in the situation. It is also vital to be aware that people have different strengths - situations that one person can cope with could be beyond endurance for someone else and this has to be taken into account. (NCO Survey)*

*Any framework should be produced jointly with carers and be at 'National' level on just local which could lead once again to post code lottery support plans. (NCO Survey)*

*Carers should be on the group that drafts the eligibility criteria and that should also recommend who else should be members of the group. (carer. Alloa)*

*Any eligibility criteria should be transparent and carers should be involved in agreeing them, reviewing their implementation and auditing the accruing evidence of efficacy (NCO Survey)*

#### Carers may not be able to access their rights

6.21 Carers were on the whole enthusiastic about the introduction of legislation, but some were cynical about its successful implementation. There were concerns that even if the duty to support was introduced, it would not be acted on and local authorities would not be held to account. This same view was also expressed by workers within statutory services who said 'It won't happen even if carers get rights'

6.22 Much of the success of the legislation will also be dependent on staff knowing about it and carers being informed of it. There is definitely a need for staff training, with several carers expressing the view that this should be mandatory for all staff from statutory agencies.

*Where a duty is put in place, it is important LAs adhere to it. There needs to be sanctions for those who do not provide carers with their rights. (Rural and Remote Carers Group)*

*Concern that if cared for are unable to access services then it will be unlikely local authorities will be able to meet the needs of carers despite legislation being in place (carer, South West Glasgow)*

*Training is essential – Carer Awareness training should be mandatory for all NHS and local authority staff (carer, Borders)*

#### Could result in greater bureaucracy

6.23 Overall carers felt that a duty to support and clear eligibility criteria would cut down on bureaucracy and carers having to jump through hoops to receive support. However, some thought that it could have the opposite effect and result in greater bureaucracy, form filling and gatekeeping.

*Could become over engineered; too rigid, crisis management (COCIS meeting)*

## **Short Breaks**

6.24 The majority of carers who either attended a consultation event or responded to our online survey indicated that they supported the proposal to introduce a Duty on local authorities to provide and promote short breaks linked to an eligibility framework

6.25 95% of carers who responded to our survey gave a positive response to this proposal and at many of our consultation events 100% of participants said Yes to the introduction of this proposal. (Coalition of Carers meeting, South West Glasgow, Alloa, and the Borders) At all the events over 90% of carers supported this proposal.

6.26 In relation to the proposal to impose a duty on local authorities to publish and promote a short breaks statement there was a similar response. 93% of people who responded to our survey supported it and over 95% of carers who attended consultation events also indicated that they supported this proposal.

*The duty to provide short breaks linked to a requirement to produce a statement of short breaks availability at last brings clarity for carers to an otherwise confused situation (COCIS)*

### **Why carers support the proposals around short breaks**

6.27 Similar to the proposal to introduce a duty to support carers and young carers, the proposal to introduce specific duties in relation to short breaks was welcomed by carers and was seen to be an important step forward. Carers see the duty as a way of achieving greater consistency in accessing short break services, having firm information on what they are entitled to and encouraging a greater focus from local authorities in developing quality short break services which would address their individual needs.

6.28 One of the reasons that carers particularly welcome the proposals around short breaks is because of the difficulty carers have in accessing a short break service. The research report 'Rest Assured'<sup>1</sup> found that over half of survey respondents (57%) had not had a break from caring. Black and minority ethnic (BME) carers were less likely to have had a break than carers overall; 63%. A significant barrier was the difficulty carers experienced when engaging with statutory social services.

6.29 Carers at our consultation events cited various barriers to not being able to access a short break, including lack of information, 'didn't know about short breaks' being told they weren't eligible and there being no suitable provision available locally.

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<sup>1</sup> Rest Assured, A study of unpaid carers experiences of short breaks, IRISS, Shared Care Scotland, COCIS, MECOPP, 2012



*Stop the endless waiting for a break, waiting for a person to leave to get their place (NCO survey)*

*At present this is a postcode lottery*

*I had to kick, scream, shout to get what I have got, and even then I was told that these places were so hard to come by, and they are quite often kept for emergency cases. But my point was who is to say that I am not going to become an emergency case if I don't get it? (carer, Rest Assured Study)*

6.30 Carers who had been able to access a short break greatly valued it as 'something to look forward to' enabling them to 're-charge their batteries' and as a life enhancing experience.

*Getting this in the last couple of years has made a huge difference to my husband and myself - a little bit of 'breathing time' is wonderful. It would have been much easier for my daughter to adjust to it if it had been offered earlier - but she now looks forward to her respite breaks after a shaky start. (NCO survey)*

## **Short Break Statements**

6.31 The proposal to introduce a duty on local authorities to publish and promote a short break statement was seen as a positive way of addressing the lack of available information on short break provision. This was also identified as an issue by carers who contributed to 'Rest Assured'<sup>2</sup> which found that not knowing how to access a short break was the most common barrier to receiving support (43%)

*Not enough clear promotion of short breaks is available, online or nothing is often the case and people still hear about services by word of mouth. Even when the*

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<sup>2</sup> Rest Assured, A study of unpaid carers experiences of short breaks, IRISS, Shared Care Scotland, COCIS, MECOPP, 2012

*local authorities provides or funds the service this is the case, definitely need to continue this provision and get a lot better at promoting it. (NCO survey)*

*All local authorities should have a shared directory of all available breaks, There should be equitable cross-charging across all local authorities (ie. a shared resource) (carer, West Lothian)*

*L.As should be aware of the opportunities that exist in their 'patch' and should clearly state where all forms of support, help and respite are available. They should actively seek to signpost carers to a Centre where the most appropriate form of support will be ascertained and the carer supported to access them (NCO survey)*

## **Concerns around implementation**

6.32 The concerns expressed by carers in relation to introducing a duty on local authorities to provide and promote short breaks and publish a short breaks statement, were broadly similar to those expressed in relation to the duty to support. They included concerns around the development of an eligibility framework, ensuring there are adequate resources for implementation, not undermining the ability for carers to access preventative services, ensuring processes are simple and easy to navigate and above all that carers are able to access any new rights.

*Definitely need more investment if short break to be a duty (COCIS meeting)*

6.33 In addition there were particular concerns raised in relation to short break services

### The definition of short breaks

The term short breaks is a confusing one for many carers and is not descriptive of the many types of support which can be accessed. Many carers thought that it only referred to support for the person they cared for provided outside the home, lasting for a few days.

6.34 Many carers explained that they required flexible services to accommodate their particular needs, so the definition of short breaks would need to be broad and this would need to be made clear in guidance.

For example, carers in both the Borders and West Lothian said the only short breaks that worked for them was a joint break away in a facility that provided additional support by trained care workers. For other people, their requirements were different, such as a group of parent carers in Edinburgh looking after adults with autism. For them unfamiliar places or people caused anxiety to the people they cared for making many options unsuitable. Only support provided in the home by a familiar person had worked.

*Need to define short breaks – as broad as possible allowing for choice (carer, Borders)*

#### Being able to access appropriate support

6.35 This was again a recurring theme, with one carer stating:

*There is no point in having a duty if carers can't get access to the type of break they need (carer, North Lanarkshire)*

6.36 The study Rest Assured<sup>3</sup> found that a key barrier uncovered through the focus groups and interviews was a lack of appropriate provision for the cared for person. In some cases, what was offered was unacceptable because it was of poor quality or because it was age-inappropriate, resulting in carers turning down

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<sup>3</sup> Rest Assured, A study of unpaid carers experiences of short breaks, IRISS, Shared Care Scotland, COCIS, MECOPP, 2012

6.37 These findings were replicated in the 2013 'State of Caring Survey' by Carers UK, which found that 46% of carers had raised concerns about poor quality care services.

*Once we hit the adult services... massive problems there because although we were approved funding, there wasn't anything to spend it on because there is nothing appropriate (carer, rest assured study)*

## **Strengthening the Duty to Provide carers and young carers with support**

In order to avoid the unintended consequences described, the National Carer Organisations are suggesting the following additions to the legislation / regulations and guidance, to ensure that the proposed duties produce the positive outcomes intended.

- **Resources** – At every event we were asked what resources would go with the Bill or 'How will this be paid for?' In order for the duty to support carers and provide and promote short breaks to be successfully implemented, resources must be found and allocated to carer support, whether from existing budgets or through the allocation of additional resources. We propose that Joint Strategic Commissioning Plans should clearly outline what resources are available to support carers and that a percentage of available resource should be directed towards carer support.
- **National eligibility criteria** - As previously stated we believe that the eligibility framework and eligibility criteria should be developed nationally and that it is essential that they are co-produced by carers

- **Preventative Support** – The introduction of an eligibility framework must not have a detrimental effect on the availability of preventative support. Eligibility criteria must take account of the need for preventative support. In addition local carers strategies should also outline their plans for providing preventative support to carers.
- **Timescales** – Many carers have faced long delays in accessing an assessment and then having the support they require put in place. This causes stress and undermines the benefits of support. We believe there should be a maximum waiting time between carers meeting eligibility criteria and receiving support
- **Portability** – When carers move from one local area to another they face the daunting task of starting again from scratch in getting support put in place. This is counterproductive and a waste of resources. We propose that a carers entitlement to support should be transferred from one local authority to another when they move and should only be reviewed if their circumstances change
 

*Portability – absolutely necessary to be able to take carers support plan with you to another LA if you move. Otherwise it is a waste of time and money (COCIS meeting)*
- **Definition of Short Breaks** – The guidance needs to include a clear definition of short breaks which should be as broad as possible, enabling carers to exert the maximum choice in relation to accessing a personalised service
- **Suitable Provision** – The success of these new duties for carers will be dependent on the quality of the services they are able to access. Carers need

to be treated as equal partners and involved at a strategic planning level and in decisions around local strategic commissioning,

- **Sanctions** – We believe the duty to support carers would need to be carefully monitored and sanctions must be imposed on local authorities who fail to comply. The government should work with local authorities to monitor implementation and ensure compliance
- **Training** – If carer legislation is to be successfully implemented staff will need to be fully trained and aware of their new duties and responsibilities. Otherwise carers will still struggle to access support. Staff training in carer awareness should be mandatory and should build on the EPiC model.

## 7. Stages and Transitions

*Transitions can be/feel ‘threatening’ – fear of unknown needs to be properly managed (COCIS meeting)*

### Statutory guidance on the Carer’s Support Plan on managing stages of caring

7.1 95% of respondents to the NCO survey agreed that the statutory guidance on Carers Support Plans should include guidance on managing the different stages of caring. Many carers at our consultation events talked about difficulties they had when the person they cared for moved from children’s to adult services or to older people’s services. Lack of information was an issue, as well as knowing what services were available, getting the right support in place and assisting the person they care for to cope with the changes. This was particularly the case with parent carers.

*Particular information, advice and support for parent carers is needed when their child is leaving the education system, especially regarding things such as advocacy and guardianship (carer, North Lanarkshire)*

*All change is difficult to cope with and anything that can have planned transition intervention is to be welcomed. However it is also important to be able to react promptly to changes outwith transitional stages so that support is given when required most. (NCO survey)*

### Young carers access to a Carer's Support Plan

7.2 98% of respondents to the NCO survey agreed that young carers should have access to a Carers Support Plan before they reach 18.

*Council should have more responsibility to support transition of young carers (COCIS meeting)*

*Not enough transition work/interagency work for young carers moving to older care due to age. Late signposting and young carers projects don't have resources to continue service (COCIS meeting)*

7.3 At the COCIS members meeting, there was also a strong feeling that appropriate services needed to be in place for young adult carers as adult carer services did not address their needs and there is no point in enabling young carers to access a Carers Support Plan if there are no available services.

*Transitions should include robust services for young adult carers up to age 23 to support them into further education and careers (COCIS meeting)*

*Preventative work to allow for positive transitions into adulthood (COCIS meeting)*

*Young carers transition to young adults services – there is still gap. Where do the young carers go to? Lost between youth and adult services (COCIS meeting)*

## **Strengthening the Proposals on Stages and Transitions**

- **Young carers** - Whilst we understand that issues affecting young carers and young adult carers are to be addressed within the Children and Young Peoples' Act, we believe there needs to be a bridge between both pieces of legislation and detail within statutory guidance and regulations on the Carers Bill relating to young carers.
- **Additional Guidance** - Guidance should include information on the development of young carer identification plans, best practice on engaging with young carers in relation to the planning of services and examples of appropriate models of support

*Young carers should be enabled to co-design the services for them (COCIS meeting)*

*There is a need for choice for young carers so they can choose own support routes to be included in the guidance accompanying the legislation (COCIS meeting)*

## **8. Carer Involvement and Planning and Delivery**

***We need information to know our rights and the right to be involved (COCIS meeting)***

### Carer involvement in the Planning , shaping and delivery of services

8.1 Carers agreed that the Bill should look at proposals to strengthen carer engagement both for planning on an individual level relating to care planning for the



person they care for and also in relation to strategic planning for service development. While carers noted that there had been some improvement in the way they are involved in care planning, most felt that they were not yet treated as 'equal partners'

8.2 This is backed by responses to the Carers Rights Charter with only 37% of carers saying they knew they had a right to be treated as an equal partner and 50% saying their experience was poor or very poor in relation to being treated as an equal partner.

*Carers should be involved in the whole process at every stage of the bill. They are the people at the front line (carer, West Lothian)*

*It should be a legal requirement for carers to be involved and for their needs to be addressed (carer, North Lanarkshire)*

### **Ensuring Engagement is Meaningful**

8.3 While carers welcomed proposals to strengthen their involvement in strategic planning, they were concerned that engagement should be meaningful and that carers needed support to participate

*Carers should be given training, support, briefings to help them to contribute effectively (carer, West Lothian)*

*Staff training is needed to recognise carers as partners (COCIS meeting)*

8.4 They also suggested that there needs to be a variety of ways for carers to have the opportunity to express their views, in order to be as accessible as possible

*Different venues for expressing their views – focus groups, online surveys, inserts in press, carers forums, carer organisations (carer, West Lothian)*

8.5 Special mention was given to the importance of engaging appropriately with young carers. It was agreed that where young carers have access to a young carer support service they were much more likely to have their views heard and to be supported to participate in planning.

*Young carers need to be included at a formal and strategic level of local planning not just the informal routes of forums or Facebook groups (COCIS meeting)*

*Integrity /involving young carers in what they want to be involved in – not tokenistic. Having trusted representation if they do not wish to be involved directly (COCIS meeting)*

8.6 Several carers mentioned COCIS's Standards for Carer Engagement as a useful reference for ensuring that carer engagement is meaningful and it was suggested that these should be build into guidance.

*Provision should include: standards developed by COCIS; involvement of carers from a range of backgrounds – including 'new carers'; ensure affordable (free) and accessible opportunities to attend events; (COCIS meeting)*

*Provision should reflect best practice standards for consultation with carers (COCIS meeting)*

#### Carer organisation involvement in the Planning , shaping and delivery of services

8.7 The involvement of carer organisations in strategic planning was welcomed. It was felt that their role would be complementary to that of carers and that they had a great deal of expertise to bring to the table. Their involvement should be in addition to carer involvement, unless it is not possible to identify a carer to participate.

*Carer's orgs can represent carers. They can represent a range of views. A rang of organisations not just national orgs – local knowledge (COCIS meeting)*

*Essential they play a key role in representing their views and acting on behalf of carers. However, there must be long-term sustainability in relation to this.  
(COCIS meeting)*

*Have the knowledge – recognition of role and experience in advocating for carers  
(COCIS meeting)*

### Statutory Provision on the development of Local Carer Strategies

8.8 This proposal was welcomed, particularly in light of the proposal to repeal Carer Information Strategies. It was felt that if this was to be the case it was important for health to remain a full partner in local planning around carer identification and support

*Health should be required to be involved. If we remove legislation health may fall away from duty of care to carers (COCIS meeting)*

*Ensure all relevant parties still meet for consultation (COCIS meeting)*

## **Strengthening the Proposals on Carer Involvement and Care Planning**

- **Making participation meaningful** – In order to ensure carers are supported to fully participate we believe the standards for carer engagement should be incorporated into the statutory guidance around the Bill
- **Young Carers** – Young carers should be supported to have their views heard by local young carers support services. They have the expertise to use interactive and appropriate methods to ensure young carers have their say.

- **Local Carer Organisations** – We support the proposal for local carer organisations to be involved in local strategic planning and believe they have a great deal of expertise to contribute. In addition, we believe that local carer organisations are best placed to support carer representatives and facilitate local carer planning forums. They should be fully resourced to undertake this work in their local areas.
- **Local Carer Strategies** - We believe that there should be statutory provision for local authorities and health boards to involve and collaborate with carers and carers' organisations in the development of a local carer's strategy. These should be connected to the national carers' strategy

## **9. Carer Identification**

### ***'More than just a flu jab' (carer North Lanarkshire)***

9.1 Many carers were frustrated at how long it had taken for them to identify themselves as a carer and access support. Often there had been many missed opportunities and they had only identified themselves as a carer when talking to another carer.

9.2 There were a lot of strong feelings around the use and promotion of GP registers as a mechanism to identify carers. Most carers agreed that their GP was most often the first port of call for them and that they needed to play a stronger role in identifying, supporting and signposting carers.

9.3 However, there was a great deal of criticism around the current use of GP carer registers, with the feeling that they were not active, failed to identify carers despite ongoing contact with them and they did not deliver any outcomes. Only 17% of respondents to the NCO survey felt that G.Ps should be exclusively responsible for managing a carer register, although 75% thought this should be a joint responsibility with the local authority.

9.4 At a consultation event in Alloa, two carers said they were on a GP register, but had not received any communication from their health practice in relation to their caring role. One said they had once received a letter. Several carers at various events said they had only received notification of their entitlement to a flu vaccination, prompting one carer to comment, 'It needs to be more than just a flu jag'

9.5 Much of the discontent centred around the fact that money is provided to GP practices to enable them to administer the carer register. This was seen to be a waste of resources.

*NO! We don't need more office jobs for the boys and girls behind desks to tick boxes on process issues : we do need to direct scarce resources towards delivering and improving outcomes that have a real impact on the quality of carers lives. (NCO Survey)*

9.6 However carers were supportive of the idea of a G.P register provided it serves more of a function in supporting carers. Suggestions included, access to longer and more flexible appointments, carer health checks, signposting to carers support services and additional support from an identified practice staff member.

*Should be an active GP carer list, i.e. it should be used to trigger carer support. There should also be a carer support trigger in the hospital (carer, West Lothian)*

*GPs have knowledge of the people who are in a caring situation within a family and would be ideally placed to check with an individual that they are aware of the ability to have their caring needs met and supported. However, with 35 years of caring behind me, I was never approached about my daughter's care needs since I had always just managed things on my own. Even when we were forced to look for medical interventions to try to help with my daughter's emotional and behavioral problems worsening in the home, no support was ever suggested and we were never asked if we were getting any outside help (which we weren't!).*

*This means that more stringent measures would need to be put in place. (NCO survey)*

*But they need to connect those registers with the providers who can help and support carers and families. No point in just number counting if it doesn't result in change for the carer. (NCO survey)*

*The current Carers Register has foundered because it lacks purpose - why simply make a list? It is clear, that the first point of contact will be the GP. There should be a clear purpose for the register. These will include talking to the carer, signposting the carer to services outwith the Practice, providing health checks for carers and keeping the signposting going as any changes in the carers' health or wellbeing shows itself. Carers will listen to GPs and if they recommend going to the local Carers Centre, they'll go. (NCO survey)*

9.7 Several groups of carers felt that G.P registers were not the route by which they would have been identified as carers. For example, parent carers whose contact with health services was mostly through specialist units, hospitals and consultants. It was felt that additional initiatives to identify carers in these circumstances need to be explored and that communication between consultants and GPs needs to be improved, perhaps with consultants being able to refer carers to their local carer register.

### **Connecting to Local Carer Organisations**

9.8 Often where G.P carer registers were seen to ne working well it was because they had good links with their local carer organisation.

**Best practice example** In West Lothian the local carer centre works closely with GP practices in the area to identify and support carers. For example in one practice they have a named member of staff who is the lead person for carers and they collaborate with the carers centre to ensure their carer register is up to date. They are pro-active in offering carers support and signposting them to other services. They also have a dedicated carers notice board.

## **Strengthening the Proposals on Carer Identification**

- **Extending the role of registers** - We believe that there should be a legislative requirement for GP practices to develop a register of carers within their practice. The coding mechanism is already in place to enable a register to be created. However, we think that there is limited value in creating a register if it is simply data collection. We believe that in addition to the identification of carers, GPs should be required to proactively refer carers for assessment and that this should be recorded on the individual patient record. We also advocate that the carers' register should trigger a review of the individual carer every six months to determine if the caring situation has changed and whether additional support is required in terms of the carers own health and wellbeing.
- **Linking with Local Carer Organisations** – There should be a named person within each practice grouping to lead on carer support. They should link with their local carer organisation, ideally this should be a joint post funded through health.
- **Other routes to carer identification** – Carers were keen to see other methods to identify carers being explored, particularly for those who do not have regular contact with their G.Ps, such as some parent carers. They also wanted to see more of a role played by local authorities in identifying carers. However, no concrete proposals were brought forward.
- **Reporting** - GPs should be required to report annually to their respective Health Boards on compliance with the GP contract. We also agree that Health Boards should, in turn, be required to report on compliance to the Scottish Government. Reporting should include: the number of carers identified within the practice, how many carers have been referred for an assessment, and how many 6 monthly reviews have been undertaken. To support this and provide a focus for

carer identification and support, we believe the appointment of a carers lead within individual practices would be beneficial.

## 10. Additional Proposal - Hospital Discharge

*'My biggest problems have been at times of hospital discharge' (Carers Rights Charter Survey)*

10.1 Spending time in hospital, either due to an emergency or a planned admission is often a time of concern and additional stress for both carers and the people they care for. This is consistently the case, both when it is the carer who is admitted to hospital and when it is the person they care for.

10.2 An admission to hospital often results in a person becoming a carer for the first time, or it can signify that their caring role is in transition as the condition of the person they care for deteriorates and there is an increase in their care needs.

10.3 Where a carer requires hospital treatment this frequently means they are unable to continue to provide care while they recover, or sometimes, due to ongoing ill-health they may no longer be able to continue their caring role or may have to re-evaluate the level of care they can provide

It is therefore essential that at these times carers have access to information and support, from the point of admission to discharge and that their views are fully taken into account when the discharge plan is put in place

*Carer support should be a part of hospital discharge planning and it should be available on discharge where appropriate (Carer, North Lanarkshire)*

**Best practice example:** Stirling Carers Centre employs two Carer Support Officers based within the Allied Health Professional team at their local hospital. They work in partnership with NHS professionals to identify hidden carers at all stages of their hospital journey, helping them to navigate their way through the system from admission to discharge. The Carer Support Officers work with carers to enable them to be equal partners in care and therefore play an active role in the discharge planning process. This ensures that the patients and their carers leave hospital with the appropriate support in place to retain as much independence as possible in their communities.



**Best practice example:** MECOPP employs two Hospital Discharge Support Workers through Change Fund monies to provide dedicated support to BME older carers and those in receipt of care who are admitted to hospital. The purpose of the project is to: identify those who come into contact with acute healthcare services; support them to actively participate in the hospital discharge process; ensure they are referred to appropriate support agencies; and, are supported to remain within the home/community setting. The project works in partnership with a similar initiative provided by the City of Edinburgh Council and NHS Lothian.

### **Carers' experience of Hospital Discharge Procedures**

10.4 A recent survey undertaken by Carers Scotland and MECOPP in relation to the Carers Rights Charter asked carers about their experiences when the person they cared for was in hospital. On both admission and discharge, dissatisfaction was high. At these key points, where carers' knowledge and experience of the person they care for is vital, very few carers feel they are treated as key partners. 39% said their experience was poor or very poor on admission and 45% at hospital discharge.

*I would pass on my observations / opinions to the district nurses attending my parents. This was either ignored or viewed as an irritation. Case in point; I expressed concern over the increasing discolouration of my mother's toes over many weeks. The nurses insisted there was no cause for concern. I insisted on calling a doctor - against the advice of the nurses. This resulted in my mother being admitted to a vascular ward in ERI, having two angioplasty procedures & three toes amputated. She was never discharged from hospital as she died four weeks after admission. (Carer, Carers Rights Charter Survey)*

*My biggest problems have been at time of hospital discharge over the past three years which have caused quite a bit of unnecessary stress following long periods of hospitalisation. A lot of it was due to poor communication and lack of attention to detail. I would say that in 5 out of 6 discharges I was definitely not*

*an equal partner and once I was made to feel that I was a nuisance! I was really upset at the time but was too tired to go through the complaints procedure and so let it pass although I know I should have taken action. . (Carer, Carers Rights Charter Survey)*

*I am so worried when the nurse tell me I am ready to leave hospital soon because I live alone and I may not have the appropriate service or equipment when I go home. However, MECOPP help me to get access to additional equipment, and also help to organize the care at home package for me so I will have the service when I go home in the next few days. It really gives me peace and I look forward to going home. (Chinese older person)<sup>4</sup>*

*It makes our work so such easier after talking to the family with help of the HDSS support worker because we know what exactly the family concerns and preference of for care are and we can start to arrange the care package for the patient. ( Nurse in Liberton Hospital Ward 2)<sup>5</sup>*

10.5 Often when people are anxious to leave hospital they do not consider the additional support they will need when they are at home and the impact this will have on their primary carer and other family members. Taking the carer's views into account is key to ensuring that appropriate support is put in place, avoiding the risk of additional stress and carer strain.

*Nobody listens to the carer's advice when hospitals, rightly or wrongly, decide whether or not to send the cared for person home. This has to change (Carer, North Lanarkshire)*

10.6 Poor discharge planning may also result in the person being re-admitted to hospital. The State of Caring Survey by Carers UK found that 37% of carers said that the person they care for was discharged from hospital too early because either support was not available or they were not ready to come home and 18% of carers

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<sup>4</sup> Innovation Fund Progress Report MECOPP 2013

<sup>5</sup> MECOPP ibid

surveyed reported that the person they care for had to go back into hospital within one month of being discharged because their health had deteriorated again and 8% within two months.

*My mum was discharged from hospital medical ward because she had onset dementia. I had my concerns about her going home to live alone and the hospital Social Work Department were unsympathetic. 4 weeks later my mum was re-admitted to hospital and is going through all of the same process as before. I have great concerns about her being discharged home again and I feel bullied by Social Work. (carer, NCO survey on carers legislation)*

10.7 Where the care provided by an unpaid carer is included within a hospital discharge plan, they should be able to specify how much care they are willing and able to provide. There should not be a presumption that family members will be available to step in and provide care on an ongoing basis. Planning needs to take account of the complexities of people's lives, such as their employment status, other responsibilities such as dependents and additional caring roles, their age and their own health and wellbeing. Unless carers are fully involved in discharge planning a full picture of what resources are required will not be achieved

*I feel the carer should be consulted more. My father said he was ready to go home so he was discharged..I had to take 2 weeks off work to care for him full time. <sup>6</sup>*

*I work full time as well as taking care of my husband who has MS. When he recently left hospital, I was not asked about the impact this would have on us, what help we had in place or if he would be able to manage in our home. He had to sleep on the sofa for 3 weeks following his release and had many*

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<sup>6</sup> State of Caring Survey, Carers UK, 2013

*bathroom accidents as both the bedroom and bathroom is upstairs and he can not reach them. Very stressful for both of us<sup>7</sup>*

### **When carers are also patients**

10.8 Where carers are admitted to hospital their discharge plan needs to take into account replacement care to ensure they are not having to provide care which may be physically or emotionally demanding while they are recovering

*Hospital discharge planning needs to include replacement care planning to ensure carers do not compromise their own recovery (Carer, West Lothian)*

10.9 At our consultation events, there were several examples provided of carers who were forced to go back to their caring role before they were fit to do so, because there was no replacement care available. One person who had suffered several aneurisms was only able to arrange a few weeks care from an elderly relative in their nineties to support her husband. She then had to resume her caring role as her local authority failed to provide her with any support.

10.10 Another carer was advised he should take three weeks off from his caring role, following an operation, but his local authority only provided support for one week.

10.11 Research by Carers UK has also found that often carers delay medical treatment, including operations because of concerns about who will replace the care they provide.

*I became ill overnight. I was hemorrhaging internally and needed immediate hospital admission. I called social services emergency line. In short it took 10 hours to get adequate help organised before I could get myself to hospital. The consultant said I was lucky not to have died<sup>8</sup>*

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<sup>7</sup> State of Caring Survey, Carers UK, 2013

<sup>8</sup> Whose Rights Are they Anyway? Carers and the Human Rights Act, Carers UK, 2008

10.12 Even in cases where carers are able to access replacement care while they recover, this is sometimes taken from their existing short break allocation, with one carer who was in hospital on a drip being told:

*you've had your six weeks respite break this year'<sup>9</sup>*

### **Proposal for a Duty on hospital admission and discharge procedures**

10.13 Despite the existing Scottish Government Protocol on Hospital Discharge, practice across Scotland differs widely and very often, to the detriment of carers. We strongly advocate that hospital discharge must begin at the point of admission with the full and active involvement of carers. Where necessary, support must be provided to the carer to ensure that their views are taken into consideration.

10.14 Discharge planning must take account of the level of care that carers are willing and able to provide and should put in place additional support or replacement care where required.

We therefore propose a **Duty on health to inform and involve carers in hospital admission and discharge procedures.**

## **11. Key Conclusions**

11.1 Carers welcome the government's plans to bring forward legislation and want it to have a **Rights Based approach** by placing firm duties on local authorities and providing them with entitlements to support.

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<sup>9</sup> Whose Rights Are they Anyway? Carers and the Human Rights Act, Carers UK, 2008

11.2 Carers also value the role that health has played in identifying, supporting and signposting carers, particularly since the introduction of Carer Information Strategies. The legislation needs to ensure that health continues to play its role in supporting carers and that the new integrated partnerships have carer participation and carer support build into their structures from the beginning.

11.3 Carers have indicated that the key priority for them is the Duty on Local Authorities to provide them with support according to an eligibility framework. For carers with an intensive caring role this will at long last provide them with a right to services they are assessed as needing. Linked to a duty for local authorities to provide all carers with an outcome focused Carers Support Plan, this will begin to address the failures and inconsistencies in the current system and mean carers will no longer have to 'battle' to get help.

### **Building a House on Sand?**

11.4 The biggest single concern about the legislation was the development of the eligibility framework. This will be the foundation on which the new rights for carers will sit. Depending on what it incorporates, it will either improve carers access to support, or create more of a barrier and a greater move towards crisis management. Carers expressed a great degree of nervousness that the details of the eligibility framework will not be included in the legislation and that eligibility criteria may be developed by individual local authorities. One carer said it felt like they were being asked to 'build a house on sand' since they don't know if the foundation will be there to support them. We therefore believe the bill needs to contain some principles around eligibility and a commitment to develop a **national** eligibility framework and eligibility criteria in partnership with carers.

### **Preventative Support**

*'Help before you hit the wall' (carer, West Lothian)*

11.5 The Minister, Michael Matheson, has made it clear that it is the government's intention for carers legislation to strengthen access to preventative support. This is

reassuring and we believe the bill must contain principles around this, backed by strong legislation and guidance. One carer from North Lanarkshire put it well when he said if the red warning light in your car goes off – would you just ignore it? – that would be an expensive mistake, so when carers ask for help, don't ignore them.

### **Building Capacity of Local Carer Support Organisations**

*Carers identify and have confidence in their carers centres. They would not welcome any encroachment by the private sector. (carer, North Lanarkshire)*

11.6 Throughout the consultation carers frequently mentioned how much they valued the support provided by their local carer organisation. They also emphasized that the support they most value is **Local** and **Independent**.

11.7 Many of the proposals are likely to impact on carers organisations, meaning they will be supporting more carers at an earlier stage. They will also be potentially providing an extended range of services, for example, if the local authority devolves its responsibility to undertake Carers Support Plans to them. Most centres are already operating at full capacity and many have been on standstill budgets for many years. The impact of this legislation on them must be scoped and they must be fully resourced to undertake any additional work.

If you require any further information, supporting evidence or wish to consult with our members in relation to any of these issues, please don't hesitate to get in touch.

Yours sincerely



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